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Development and Testing of the Palliative Care-related Knowledge, Attitudes & Confidence in Home Health Care (PC-KAC in HHC) Questionnaires

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BACKGROUND

- Palliative care provides patient- and family-centered care to individuals with serious illness.[1]
- Home health care (HHC) utilization is increasing in both the U.S. and Europe due to an aging population and patients with multiple chronic conditions,[2-3] leading to a great need for palliative care in HHC.[4-5]
- However, it is unclear if HHC clinicians are prepared to provide such care and how palliative care is perceived by HHC patients and their informal caregivers.
- Currently, there are no setting-specific survey instruments to measure palliative care-related knowledge, attitudes, and confidence (PC-KAC) among HHC clinicians, patients, and caregivers.

STUDY AIM

- This study aimed to develop and test PC-KAC in HHC questionnaires for use with clinicians, patients, and caregivers providing/receiving care from U.S. HHC agencies.

METHODS

- Guided by the 2018 National Consensus Project Clinical Practice Guidelines for Quality Palliative Care (NCP guidelines),[6] we developed two PC-KAC in HHC questionnaires: 1) for clinicians, and 2) for patients/informal caregivers.
- We conducted a comprehensive literature review, identified existing survey instruments measuring PC-KAC, and adapted scales/questions to the HHC setting.
- The questionnaires were refined through feedback from experts in palliative care and HHC, as well as cognitive interviews with HHC clinicians, patients and informal caregivers.
    - Cognitive interviews were conducted individually over phone, Zoom or Facetime with 10 home healthcare clinicians (5 nurses, 3 therapists and 2 social workers) and 10 patients and caregivers who were given questionnaires to review prior to the interview.
    - During the interviews, we asked interviewees about: 1) questionnaire length; 2) understandability; 3) comfort; and, 4) suggestions.
- Pilot testing will be conducted with 30 clinicians and 30 patients/informal caregivers from a large, urban HHC agency to assess validity and reliability.

RESULTS

- Our PC-KAC questionnaires are organized by 3 main sections: knowledge, attitudes and confidence; each section contains items relating to the NCP guidelines eight domains of practice (see **Table 1**).
- There are core questions, as well as clinician role-specific (for nurses, therapists, social workers) and caregiver-specific items.
- Questions about demographics, as well as preferred communication methods, information sources and location of palliative care services, are asked at the end.
- During cognitive interviews, we received specific feedback about the questionnaire length, questions/topics included in questionnaire, and response choices.
- Overall, the questionnaire time from start to completion ranged from 30-45 minutes for clinicians and 20-35 minutes for patients and caregivers.
- From **clinicians**, we heard:
    - The questions were not confusing, but some participants noted they are not that confident in providing palliative care, but understand hospice.
    - That we should consider giving a directive that not all response choices may be true (for knowledge questions).
    - Physical therapists might have a harder time recognizing the generic pharmaceutical names cited in the knowledge section.
    - It would be beneficial to provide more clarification or a definition regarding Medical Order of Life-Sustaining Treatment (MOLST) forms.
    - The terms "legal primary caregiver, Power of Attorney, or established healthcare proxy" were preferred in place of "surrogate decision maker".
- From **patients and caregivers**, we heard:
    - The questions were easy to understand, but some patients and caregivers felt a few questions needed more clarification or they had no experience of what was being asked.
    - More questions about caregiver appreciation should be considered.
    - Talking about how palliative is different than hospice might be beneficial (in the survey's definition of palliative care) as people equate palliative care to dying.
    - The term "health care proxy" was preferred in place of "surrogate decision maker".

"Not really sure what palliative care is based on definition given — doesn't really come 'alive'. Add living examples that are quick to read."
-Caregiver

"I don't know much about palliative care in general, but I do not think you are really missing anything."
- Social worker

Table 1. Structure of the PC-KAC in HHC Questionnaires for Clinicians, Patients and Caregivers

CONCEPT/AUDIENCE	KNOWLEDGE		ATTITUDES		CONFIDENCE	
	PATIENT/ CAREGIVER	CLINICIAN	PATIENT/ CAREGIVER	CLINICIAN	PATIENT/ CAREGIVER	CLINICIAN
DOMAIN	NUMBER OF QUESTIONS					
Structure and processes of palliative care	19	5	5	9	1	4
Physical aspects of care	4	19	5	2	2	5
Psychological and psychiatric aspects of care	1	6	3	1	1	1
Social aspects of care	0	2	0	3	0	1
Spiritual, religious, and existential aspects of care	1	2	0	2	1	1
Cultural aspects of care	2	2	2	3	2	1
Care of patients nearing the end of life	2	5	3	10	1	2
Ethical and legal aspects of care	1	5	0	3	0	1

"Although the survey is long, I like the response options of 'don't know' and 'unsure'. The sections and questions flow."
- Physical therapist

"In having conversations about palliative care, you might think you were dying and have a realization of how serious your illness is…"
- Patient

CONCLUSIONS

- Our PC-KAC in HHC questionnaires will be the first HHC setting-specific survey instruments to measure PC-KAC among U.S. HHC clinicians, patients, and informal caregivers.
- While the questionnaires were developed and tested in the U.S., they can be adapted for different cultures and countries.
- Study results will help inform clinical practice to ensure provision of high-quality palliative care.

REFERENCES

1. Saunders C. The evolution of palliative care. J R Soc Med. 2001;94(9):430-432.
2. Avalere Health. Alliance for Home Health Quality and Innovation (AHHQI) Home Health Chartbook 2021. https://ahhqi.org/images/uploads/AHHQI_2021_Home_Health_Chartbook_FINAL.pdf. Updated September 30, 2021. Accessed November 13, 2021.
3. Genet N, Boerma WG, Kringos DS, Bouman A, Francke AL, Fagerström C, Melchiorre MG, Greco C, Devillé W. Home care in Europe: a systematic literature review. BMC Health Serv Res. 2011 Aug 30;11:207.
4. Stober M. Palliative Care in Home Health: A Review of the Literature. Home Healthc Now. 2017;35(7):373-377.
5. Sánchez-Cárdenas MA, Garralda E, Arias-Casais NS, Benitez Sastoque ER, Van Steijn D, Moine S, Murray SA, Centeno C. Palliative care integration indicators: an European regional analysis. BMJ Support Palliat Care. 2021 Sep 13:bmjspcare-2021-003181.
6. Ferrell BR, Twaddle ML, Melnick A, Meier DE. National Consensus Project Clinical Practice Guidelines for Quality Palliative Care Guidelines, 4th Edition. J Palliat Med. 2018;21(12):1684-1689.

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